Understanding the importance of illness narratives in people with multiple sclerosis who participated in an exercise rehabilitation trial; a qualitative study

Soundy, Andrew; Dawes, Helen; Collett, Johnny ; Coe, Shelly; Rosewilliam, Sheeba

Understanding the Importance of Illness Narratives in People with Multiple Sclerosis who Participated in an Exercise Rehabilitation Trial; A Qualitative Study

Soundy, Andrew; Dawes, Helen; Collett, Johnny ; Coe, Shelly; Rosewilliam, Sheeba

Arch Physiother. Rehabil. 2018; 1 (1): 001-020 DOI: 10.26502/fapr001

Research Article

Understanding the Importance of Illness Narratives in People with Multiple Sclerosis who Participated in an Exercise Rehabilitation Trial; A Qualitative Study

Andy Soundy[1*], Helen Dawes[2], Johnny Collett[2], Shelly Coe[2], Sheeba Rosewilliam[1]

School of Sport, Exercise and Rehabilitation, University of Birmingham, Birmingham, UK
Centre for Movement, Occupational and Rehabilitation Sciences, Oxford Brookes University, Oxford, UK

***Corresponding Author:** Dr. Andy Soundy, School of Sport, Exercise and Rehabilitation, University of Birmingham, Birmingham, West Midlands, B15 2TT, United Kingdom, E-mail: A.A.Soundy@bham.ac.uk

Received: 01 October 2018; **Accepted:** 08 October 2018; **Published:** 15 October 2018

Abstract

Objectives: To understand how illness narrative master plots may be expressed and associated together and to determine how stories are used to demonstrate the psychological benefits of exercise rehabilitation.

Design: A subtle realist paradigmatic position was assumed which utilised a hermeneutic phenomenological methodology.

Setting: Two community centres within the UK.

Participants: A purposive sample of 10 individuals with MS (7 female, 3 male) were included. Individuals were eligible if: (a) they had undertaken at least 8 weeks of an exercise rehabilitation trial, (b) if they were older than 19 years, and (c) could understand English.

Intervention: Participants had undertaken at least 8 weeks from a 12-week cycle ergometer randomised control rehabilitation trial. The trial varied the exercise intensity experienced by participants.

Main Outcome Measure: A single semi-structured interview with six sub-sections that included elements related to emotional regulation. A categorical content narrative analysis was undertaken. The analysis was supplemented by integrating findings from past research studies.

Results: Two themes were identified: (1) Identification of a model of narrative expression. This model establishes how narrative master plots may be associated with each other and broadly represent coping or succumbing responses to the experiences of MS. The transition in expression of master plots is detailed and associated with psychological adaptation to illness (2) The role of physical activity in contributing to psychological benefits of exercise rehabilitation identified through narrative expression. This research highlighted a dominant process of narrative master plot expression from detective, to didactic and then heroic master plot.

Conclusion: The research has developed a new model for understanding the cycles related to dominant master narrative plots. Further work is needed to establish these results and future studies are needed to establish if there is feasible way to use illness narrative within clinical environments.

Trial registration: Trial registration number: ISRCTN89009719.

Keywords: Multiple Sclerosis; Exercise; Qualitative; Model; Narrative; Hope

1. Introduction

Multiple Sclerosis (MS) impacts the physical, psychological and social wellbeing of about 2.5 million individuals worldwide [1]. Within this population mental comorbidity is nearly three times (OR 2.94, 95% CI: 2.75-3.14) more likely compared to the age and gender matched general population [2]. The most prevalent forms of psychological ill health include depression and anxiety [3-4]. Depression has a prevalence in MS of around 30% and 22% for anxiety [5]. Moreover, the emotional distress experienced by individuals with MS can increase four-fold when symptoms progress, effecting social and psychological functioning [6]. Without doubt considerable psychosocial resources are needed to help individuals cope and adjust to the impact of MS [7].

A central process to enable positive coping and psychosocial adaptation is the ability to access, master and reintegrate meaningful activities, roles, and relationships [8-9]. This is especially important given that the ability to obtain satisfaction from meaningful behaviours is significantly reduced in individuals with MS compared to age matched controls [10]. The mastery of such behaviours will be associated with positive emotions and a better ability to cope thereby promoting mental well-being [11]. Indeed, the ability to adopt an optimistic view has been associated with reduced depression, reduced negative affect but also increased positive affect and better adjustment [1]. This adoption of an optimistic view could be discerned in some behaviours following MS, one of which is the engagement in exercise rehabilitation. Voluntary engagement in exercise rehabilitation demonstrates a positive stance towards the deteriorating effects of the illness. It also establishes a personal effort to battle against the MS related symptoms [12]. Participants with MS who engage in exercise rehabilitation could be seeking to self-regulate their own behaviour and improve perceived control over their circumstances [11, 13, 14]. Further it has been previously identified that group participation promotes a shared appraisal of illness [15], elicits common strategies of emotional regulation [16] and is associated with improvement in positive affect and perceived personal

competence [17]. Thus, it is likely that such benefits experienced within the exercise groups help generate and enable mental well-being and broader psychological growth [8] for individuals with MS. This would potentially indicate that they have initiated a hopeful response towards the illness accessing agency and pathways to allow hope [18] to be established through exercise, but also establish hope by embracing what has happened, as against feeling hopeless [12, 19]. Maintaining mental well-being and hope is likely enhanced by establishing an ability to cope and this may be created through a coping cycle that counters the effects of loss from the impact of the disease progression and symptoms [20]. Research is required to establish if such a process exists following engagement in exercise rehabilitation and understand the value for people with MS.

The ability to experience hope and establish coping strategies or experience hopelessness and succumb to the effects of illness can be captured by the patient's illness narrative. Illness narratives reflect stories told by patients about their experience of an illness, the story often has a plot that is identifiable and recognisable by others containing a beginning, middle and end [21].The stories told by people with MS have been associated with common 'master' plots [19]. These stories to some extent represent a shared experience of an illness for people with MS [22]. Illness narrative master plots reflect experiences that can be separated by the focus they have on the individual's response to the loss or change that has occurred and the subsequent processes involved in adaptation. Master plots which reflect an initial psychological adaptation response (as captured by state and phase models of illness adjustment [23]) to the identification of illness change and loss, possibly at diagnosis, or during an exacerbation of symptoms. These master plots include; (a) plots that represent shock and an inability to comprehend the loss, (b) plots that seek full restoral of life as it used to be before the illness (restitution master plot) and (c) plots which illustrate the irreversible damage and hopelessness of the situation (chaos master plot). Other master plots illustrate the opportunity to navigate and (re)interpret the impact of loss, this includes realising the personal need for information regarding the illness, as well as the response to that need in a more active (an individual process that is undertaken) or more passive way (receiving information only from others) [9]. These master plots include; (a) plots which illustrate searching/receiving information regarding the illness diagnosis and prognosis named the detective narrative and (b) plots which illustrate the expression of information learnt through the experience and information gathering named the didactic narrative.

The final group of master plots illustrate a process of finding meaning [24] and coming to terms [22] with the present effects and impact of loss. They vary by their emotional response to loss, the ability to acknowledge and embrace loss as well as the ability to cope and find hope in the present and future circumstances [19, 22]. These master plots may include; (a) an inability to embrace, accept or reflect on the impact of illness, namely the restitution narrative and chaos narrative, (b) an ability to embrace circumstances and find value and meaning resulting from the loss, these include the supernatural narrative and quest narrative and (c) an ability to identify and use effective strategies to overcome the difficulties faced, these narratives are called heroic. Despite this classification of illness narratives, research has not established how narrative master plots may be expressed together within a cycle of ongoing psychological adaptability. Additionally, how any particular response may be maintained within a group of people who take up exercise rehabilitation. Specifically, if the benefits attributed to exercise

rehabilitation reflect past suggestions of self-regulation and emotional regulation, personal competence and shared appraisals of illness. Thus, the dual aim of this research was to; (1) understand how illness narrative master plots may be expressed and associated together and if there are specific cycles that help maintain a more dominant master plot (2) determine how stories are used to demonstrate the psychological benefits of exercise rehabilitation.

2. Methodology

A hermeneutic phenomenological qualitative approach was undertaken. This design is positioned within the subtle realist paradigm [25]. Traditional reporting is assumed according to the COREQ guidelines for reporting interview studies [26]. Analysis of findings is enhanced by integrating past literature into the present findings. The purpose of this is affirm and critique the common realities identified by the expression of narrative master plots.

2.1 The qualitative researcher

Semi-structured interviews were done with all patients by one researcher, AS, white male, aged 30 years. At the time of the study AS had 3 years post-doctoral experience using qualitative approaches and past training in qualitative methods. The group had no previous interaction or relationship with AS. They were told of the aim of the research through an information sheet and the purpose of the interview by another researcher (JC) who assisted their exercise rehabilitation program. Researcher JC invited people with MS to be interviewed between week eight and twelve of an exercise rehabilitation programme.

2.2 Setting and context

Interviews were conducted in two locations: a rehabilitation centre in Oxfordshire and a MS Society location in London. Both settings were selected because participants were already attending the locations and this reduced participant burden (i.e., travel and time). The interviews took place in a quiet room at both locations convenient for individuals and enabling access. Participants were identified from trial (Trial registration number: ISRCTN89009719). The trial [27] included 61 participants. The median Barthel index for this group was 19 with a range of 13-20. The mean and standard deviation for the fatigue severity scale was 4.6±1.1 and for the SF-36 was 58.6±16.9. This clinical trial involved random assignment to bi-weekly 20-minute exercise sessions on a static cycle for 12 weeks with assignment to one of three intensity groupings.

2.3 Sampling strategy

Purposive sampling of individuals who had undertaken at least 8 weeks of the exercise rehabilitation class was undertaken. Participation was not restricted based on types of MS, duration of disease, age, gender or socioeconomic backgrounds. Individuals were excluded if they were less than 18 years old and could not understand English or provide written consent.

2.4 Ethical approval

Ethical approval for the qualitative study was obtained from the Department of Physiotherapy at the University of Birmingham [12].

2.5 Data collection methods

Semi-structured interviews (Supplementary File Appendix A). were conducted. The interview guide comprised of six sub-sections exploring: the illness, hope, exercise, control, information and interaction. These sections were based on expert opinion and a-priori theory [12, 16, 19, 22, 28]. The concepts included were relevant to psychological adaptation which underlie different narrative master plots [22, 29] and relate to emotional regulation [11, 16, 28]. No changes were required in the question guide following preliminary data collection.

2.6 Analysis and Sample Size Considerations

Five stages were undertaken. All recorded interviews were transcribed verbatim. Stage 1 included a framework analysis was used which groups verbatim responses in previously established illness narrative master plots [19, 22]. Stages 2 included an initial process of grouping the verbatim responses within each plot by particular considerations; (a) the definition of the plot, (b) how physical activity related to this plot, (c) the association of this narrative plot to other plots and (d) the factors that influence this narrative plot. Stage 3 reduced and focused the content by; (a) considering the narrative plots with the most clear and extensive consideration from the interviews or common realities expressed participants. Stage 4 refined information from stage 3 and integrated past literature (supplementary file Appendix B) to allow agreed consideration of the common narrative plots. This allowed critical consideration of the common master plots, a greater focus on the results obtained and as a result achieved greater information power [30]. This provided justification to our sample size and utilisation of additional literature to gain information power. Stage 5 identified a critical consideration of the association between the different common plots, this information was then juxtaposed [31] and considered it could represent a model; the narrative model was based on the model of hope enablement which reflects a coping and succumbing response to illness. Finally, a line of argument synthesis [31] was made to suggest how, based on current understanding the expression of common master plots are associated with underlying psycho-emotional concepts.

2.7 Trustworthiness

Trustworthiness is considered by the use of reflexivity (see below), a completed modified COREQ guideline assessment (Supplementary File Appendix C) and an audit trail with each stage of analysis is given in (Supplementary File Appendix D). The use of past literature was intended as a synthesis technique which would establish if the representation of the common realities were accurate and if they should be critiqued further. The purpose was exam past literature within the scope of the current results, the purpose was not to consider any alternative findings.

2.8 Patient and public involvement

Patients were not involved in the development of this study.

3. Results

A purposeful sample of 10 patients (7 female, 3 male) consented to participate in this research study. Patients were diagnosed with secondary progressive MS (N=6) and relapsing remitting MS (N=4). The patient's average age was 55.7 years (age range 44-69 years) and average time since diagnosis was 17.4 years (time range 5-40 years). Table 1 provides demographic details of these individuals. These demographic details are summarised along side verbatim quotes including participant, gender, number, age, type of MS and time with diagnosis; e.g., PF1 61 SP 27. Stages 4-6 was supported by past literature that included 4 research studies that considered illness narratives [32-35] and 5 research studies that considered the experiences of exercising [14, 36-39].

Participant gender and number	Age	Type of MS	Time since diagnosis (years)	Marital Status	Work status
PF1	61	SP	27	Single	Retired
PF2	51	SP	11	Divorced	Unemployed
PF3	60	SP	12	Married	Retired
PM4	56	RR	15	Single	Unemployed
PF5	66	RR	25	Widowed	Retired
PM6	44	SP	13	Single	Unemployed
PM7	69	SP	40	Married	Retired
PF8	52	RR	5	Married	Unemployed
PF9	52	SP	15	Married	Unemployed
PF10	46	RR	11	Married	Unemployed

Table: The demographic details of participants. Note: SP = Secondary Progressive; RR = Relapsing Remitting.

3.1 The expression of the analysis

The results focussed on two main themes: (1) The identification of a model of narrative expression that suggests association between the identified different narrative master plots. (2) The role of physical activity in contributing to psychological benefits of exercise rehabilitation identified through narrative expressions. The supplementary file provides evidence of these expressions i.e. verbatim quotes and definitions of the core narrative types (see Supplementary File Appendix D).

3.1.1 Theme 1: Identification of a model of narrative expression: A model was created which identified how narrative master plots were associated together. The model indicated the presence of a coping and succumbing response to illness [20]. The coping response seemed dominant for the current participants. This response was

represented by three distinct narrative master plots, namely the detective, didactic and heroic master plots. The most common movement in these master plots are considered below.

3.1.1.1 The core expressions of searching and learning: The participants were slowly able to integrate the impact and assimilate meaning of the MS related symptoms through searching for information and learning from experiences. The role of the detective narrative master plot was to identify; (a) what the problem is and what was/is wrong, (b) what do/does the symptoms/illness mean for the individual's life and (c) what now can be done about it. Pre-diagnosis or near diagnosis, the search for the possibility of hope in medical interventions or supernatural restoration appeared dominant. However, for most this changed. For instance, PF1 61 SP 27 stated: "*Early on I just wanted to get better, and I did. But then when I went into secondary progressive…it kept getting worse… I still haven't come across anyone who's had secondary progressive who actually [has] come though it and come out of it and [then] led a normal life*."

Following diagnosis, a broader search for what was possible through interventions that could enable, enhance or maintain living appeared more dominant. The process of searching enabled a focus on present and future roles, circumstances and goals. This process assisted and promoted acknowledgement of one's present situation (which is regarded as essential for mental well-being [9]). But for most in the group it ended with an acceptance that a cure would not be available for them. PM4 56 RR 15 illustrates this process:

I've had a look to see what I can do to help myself, I've gone thought the diet routes….I did go for the coat-serum trial… I did put myself forward for that drug trial, it's the first time I fitted all the criteria…. I have reached the stage now where it is a progressive illness and … you read about some new treatment or drug…you know it is going to be 5 to 7 years before anyone is benefiting from that.

The didactic narrative master plot appeared to focus on what has been learnt since the first symptom was presented. The learning included an appreciation for the manifestation of the illness and the relative and perceived impact and change caused by the MS. PF9 52 SP 15 Illustrates this journey clearly:
I was told that I had relapsing remitting MS…soon after…I went to Scotland and I did some mountain climbing…I can remember getting to the top of this mountain and it was quite difficult …I found it a little strange because I have always been very fit…I found it very very frustrating, but then four years ago I started to get more symptoms and it affects my legs now particularly my, excuse me, my right leg and err, my right leg has just deteriorated quite a bit [PF9]

There were several critical lessons reported: (1) understanding symptoms and learning the benefit and potential in medicine, (2) learning to modify hope from a cure to the possibility (for some this was an unrealistic possibility) of a cure and (3) learning to live with significant and often unpredictable events and adopt self-regulatory processes which facilitated focus on living in the present and adapting to future change [19]. This adaptation and self-regulation aided the ability to initiate, maintain, regain or restore meaningful roles, activities or interactions.

3.1.1.2 The searching and broad shift in searching: A critical point in an individual's journey with MS for changing narratives appeared to be the beginning of a search for meaning and understanding of the loss and change that was occurring as a result of MS. Much of this learning was reflected by expressions that detailed coping was possible. This expression was reflected by illustrating that they could overcome challenges presented by the MS related symptoms and that the lessons learnt broadly were that coping could be maintained and this enhanced mental well-being. This learning often reflected a common knowledge about 'pathways' (ways to achieve the desired outcome) and often illustrated a common agency when approaching exercise rehabilitation (this includes the motivation and determination to undertake any given exercise rehabilitation task).

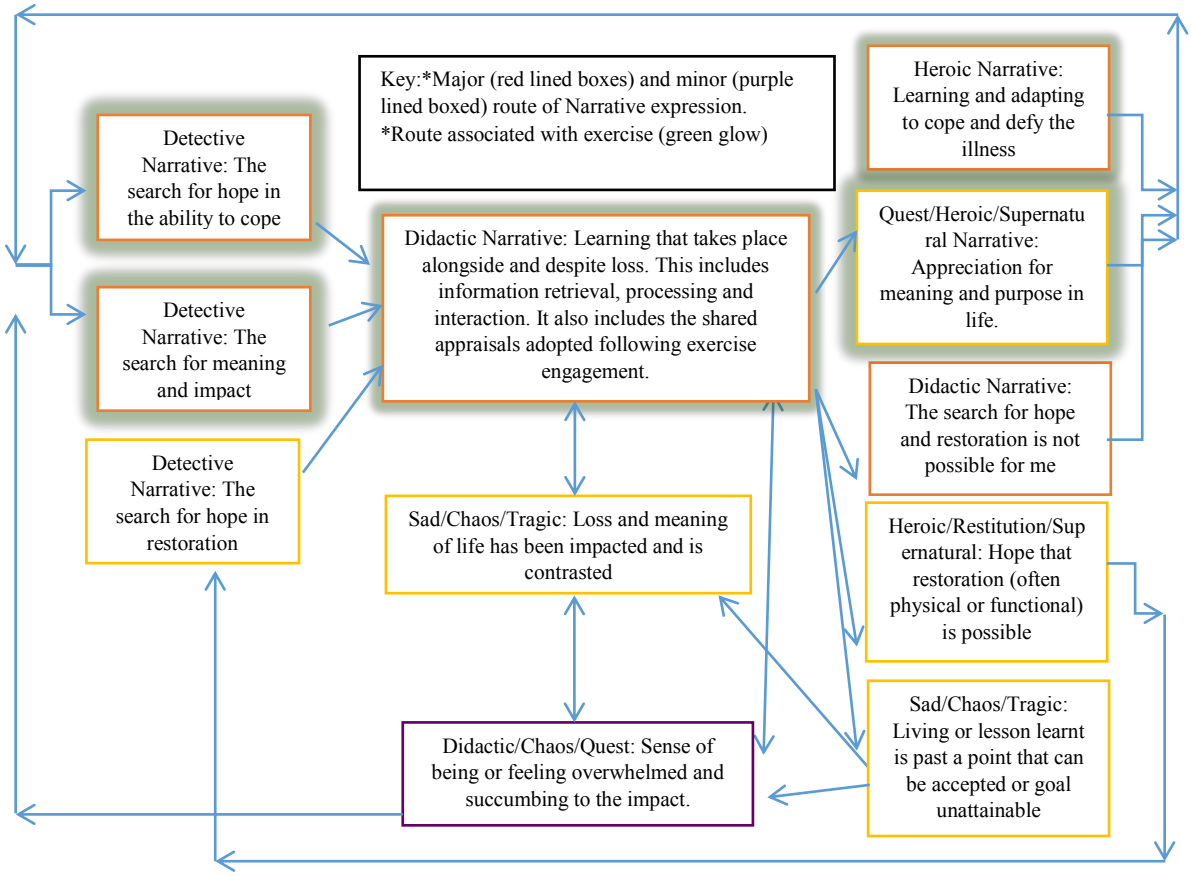

Figure 1: The cycle of macro illness narratives told by individuals with Multiple Sclerosis.

The detective, didactic and heroic master plots appeared to represent core narratives that would, for this group, focus on an establish cycle, refined by their own personal learning and experiences. This resulted in a unified narrative expression with regards to how coping strategies were established and used across the groups. The searching and learning cycles influenced psychological adaptation and resulted in stories of the past that included a degree of acceptance towards the change that had occurred. Most participants identified that there was a certain distance to the

lived experience. One reason for this would be the acknowledgement that hope of a cure from treatments wasn't possible, after repeated cycles of experiencing new treatments without any significant impact or change from them. The master plots that followed the detective and didactic narratives often represented the impact and meaning of lived experiences for individuals in the present. These master plots typically reflected the emotional impact and ability to adapt and cope with the unpredictable nature of the MS related symptoms. These master plots appeared to lead towards a cycle of adapting and coping or a cycle of succumbing. The model of narrative expression (MONE) identifies a single searching and learning process with illustrations of dominant cycles identified by participants in the current group (see Figure 1).

Three specific considerations to the model were observed: first, participants in the current study appeared to have slowly accumulated repeated cycles of searching and learning. Some participants were close to this process and demonstrated a great need for a cure and almost a reliance on the searching process which would eventually give hope. PF9 52 SP 15 stated: '*I find I get up to date information about what's happening. And also…I've done, research with…a hospital in Cambridge and I have spoken to the girl there…, she interviewed me …and people like that I find that they have more up to date information than my local GP, sadly…it's a frustrating issue, because, to put it another way I am just bloody minded and I won't give up*.' A slightly more desperate search for information was presented by PF8 52 RR 5; '*AS: how have you found the information about your illness? From people, from research, from… P: everywhere, internet, people, doctors…my family, most of them are doctors you know, so I ask all of them…a neurologist…I have two plastic surgeons, and I asked them as well. All the doctors in my family the doctors in [name of country]…with my doctor in [name of country], is more easy [as I can speak to them in my native language]. Everyday, you know, so if I have a call someone to ask [about information relating to her condition] I call all the people and no one helps. Because no one tells you something really, that you can say ahhh, well something nice is going to happen*.'

As part of the searching process and detective master plot, a shift in the search-learning cycle seemed to occur for most participants. This was from treatments and focus on a cure for MS towards coping and management of MS. The repeated cycles appeared to provide a greater ability to reflect on what forms of coping are useful to promote engagement with meaningful interactions and activities. This process appeared to reflect a certain ability to be less overwhelmed or emotionally impacted by the uncertain progression of MS related symptoms. PM4 56 RR 15 states:

Much more effective [than searching for a cure] is learning to cope … I found that getting dressed myself was gradually getting more and more difficult and you are having to adapt your shoes and clothes [to make it easier]…then I reached a point where I needed my mother's help to get dressed…, because she can do up shoe laces, so you can wear shoes that you haven't worn for a long time and you can go back to shirts that are difficult to button because she's going to button them, so err, in a way, I wish I started that earlier.

The heroic master plots often illustrate stories of coping that identified how this group of participants faced the progressive nature of the illness. Heroic acts represented an ability to accommodate the continued loss in a way that

allows functioning to continue. Thus, change in the current group appeared to occur from the hope of being restored or regaining what was lost towards acknowledging that these hopes may not be possible, that other hopes are possible, and that the hope of being able to cope and continue what is valuable is most attainable. This shift in hope is represented theoretically by the movement from expressions linked to the dichotomy of hope (having hope of restoration to having no hope) towards expressions linked to the paradox of chronic illness [40] (the ability to acknowledge one's present situation and the impact it is having on one's life is expressed simultaneously as statements, actions and behaviours which demonstrate a want or need to defy the situation [19]).

Second, dual or contrasting narrative master plots were often expressed simultaneously. This reflected most often a dual expression representing a heroic master plot and sad master plot. The dual expression could be seen in the following ways; first, the participants could contrast the sadness at the losses experienced in the present when contrasted to what life used to be like pre-symptoms (including losses in roles or social identities, activities and interactions). This could be expressed alongside an illustration of defiance towards the impact the MS related symptoms has had. For instance, this could include overcoming challenges presented or making no modifications to one's life style and continuing 'normal living' for instance a PF2 51 SP 11 stated:

"*I sometimes have my thing, you know I wish things were better, but I know there are not going to be, but I accepted [this] a long time ago… [a member of family with MS] wouldn't have any help, and I think that is what gave me the fight to say I am not going to give into this*".

Third, losses experienced could influenced dignity of living, create a sense of shame and be so great that they could represent that it was futile to work against it. In contrast, many individuals in the current study demonstrated an ability to continue to develop, maintain or renew coping strategies despite the ongoing cycles of loss. The relative loss and impact was observed between participants. For instance, PM6 44 SP 13 stated: "*I mean took me about a year to get on top of it, I thought, I have got this, there is nothing they [medics] can do about it, I can cry about it, [that would] get me nowhere so…so [I] just get on with it, that's it*.". Whereas PF1 61 SP 27 stated seemed to represent the impact further:

'*I kept expecting it to get better, but it didn't and it kept getting worse. And whatever I could do one year the next year I could do less. And as I say I didn't want to think I was in secondary progressive because that was too awful because I knew what would happen I knew [that] it was slow disintegration. And I knew it would put a stop, a hold on, well, a complete stop on my life as I knew it. Erm but eventually I had to come to terms with it…I do what I supposed to do and you work hard and you know you do the trials and all sorts of things. But you're just working hard to stand still or get worse, because its progressive… And so, you just use up a lot of effort to get somewhere that you don't want to be anyway*.'

The heroic master plot appeared to be linked to the sad, tragic or chaos narrative master plots by acknowledging that nothing can be done to change the outcome, rate and uncertainty surrounding the change and deterioration created

by MS. For individuals in the study the meaning of loss appeared to be relative; where the losses are perceived to be large or very recent this narrative would reflect a tragic master plot, where no hope could be found it could reflect a chaos master plot.

3.1.2 Theme 2: The role of physical activity in contributing to psychological benefits of exercise rehabilitation identified through narrative expression: Two clear sub-themes were identified. First, from past literature it was identified participants needed to acknowledge that it was appropriate to participate in exercise rehabilitation. This would occur through the very initial contact with professionals. Once this is established, it appeared apparent that exercise rehabilitation was able to create and promote a dominant cycle that related to coping and overcoming barriers and challenges presented by the MS. Exercise appeared to create a cycle of learning, testing and understanding what functionally is possible and not possible, what one's limits are in a safe environment and identifying how it can be overcome. Thus, it was apparent that exercise rehabilitation appeared to be associated most clearly with experiences that related to heroic master plot. Thus, it appeared that taking part and engaging in exercise appeared to be fundamentally important for the mental well-being of individuals with MS.

Second, the current results illustrated that repeated exposure to the exercise rehabilitation environment (setting, instructors, peers and others) could generate a positive learning cycle which would evolve pathways to enable coping and maintain agency and resilience against the unpredictable and changing MS related symptoms. The benefits were established through several references to coping practices that were identified. This included; witnessing other patients' journey's and the benefits they had identified. This appeared to helped create shared appraisals of illness, for instance one participant [36] stated: "*If anybody with MS is carrying a load of trouble on their shoulders then they come here, many others have the same problem*." The relatedness with others help provide an agency [18] to the response for instance one participant stated [39] '*I think because everyone is in the same boat, it stops you from feeling sorry for yourself, feeling oh I can't do this, you see everybody else getting on with it and it inspires you to try harder*.'

The learning generated modification of planning and pacing activities or pathways [18] for coping for instance one participant [38] stated: " *I now take care before I do something, I think 'Can I do it?' 'Am I capable of doing it?' 'How I am going to be afterwards?' and therefore live my life along them lines, a lot more stress free*". In the current study the exercise rehabilitation group appeared to help establish several narratives which were didactic in nature this included establishing; (a) safe forms of activity and (b) the limits of activity and the understanding of how energy reserves and the need to pace activities are important. This can be illustrated within past literature for instance one participant [14] stated: '*you have to find the proper balance…'Do I want to vacuum or do I want to play with my grandkids, because I won't have the energy to do both*". And (c) roles now possible, activities or interactions that are not possible.

Thus, the exercise group appeared to enable patient led strategies for successful emotional regulation and coping. Exercise also provided a safe environment to establish the possibilities of action, identification of the value in

challenging the illness, reassurance of capability and identification of what is safe, an opportunity to battle against the illness and a positive learning environment. For instance, PF1 61 SP 27 stated: "*you always think with MS that, ermm, exercise is going to make you tired. But I found that my fatigue levels dropped enormously once I was doing more exercise which seemed totally illogical but its proved it, you know it's important*." Being able to see and hear from others that support the living out of a heroic narrative master plot.

Other illness narratives associated with exercise should be considered. Exercise can provide an opportunity to focus expressions away from a sad narrative for many reasons for instance; the environment accessed, the support and comparisons available, the group ethos/culture or the gains achieved. For instance, PM7 69 SP 40 stated: "*See I'm strong enough to sit up from this chair*". Participation in exercise is an opportunity to overcome the tragic experience. Exercise is also an opportunity to react against the chaos of MS and change what may have previously been considered as a certain situation.

In summary, the exercise group appeared to aid navigation towards an optimal way of living with hope, by enhancing the ability to adapt and cope with MS. The shared appraisals of illness and experiences in the group appeared to provide access to narratives which may most effectively overcome the difficulties with MS. These findings appeared consistent across others studies.

4. Discussion

The current paper identifies a model of narrative expression which relates to the perceptions and experiences in a group of people with MS participating in exercise rehabilitation. This research is able to document the role physical activity has in relationship to the narrative master plots. It is further able to translate past findings about the psychosocial benefits of exercise rehabilitation by examining participants' narrative expressions. The experiences of participants with MS suggested that exercise is a positive behavioural intervention, which may have benefits akin to other positive psychological interventions. In particular this may include increasing positive emotions, enabling and enhancing the ability to cope and the establishment of emotional regulation. This may provide a protective effect against negative emotions. The results illustrate a need to consider if association between emotion, psychological adaptation and hope exists. The results also provide evidence for a need to understand how narrative expression may change and to understand why this expression changes across the illness experience. The discussion now goes on to consider the transition in narrative expression, the role of the exercise group and factors that can influence the narrative expression within this context.

4.1 The transition in narrative expressions and proposed mechanisms

Individuals were unlikely to express just one dominant illness narrative master plot. Dual narrative master plot expressions that were told often illustrated contrasting views on hope and adaptation. These expressions appeared to be associated with the processes involved with the ability to psychologically adapt to the circumstances faced. However, further details are needed to consider process and change from any dominant singular master plot

expression towards a dual expression and establish the factors which may influence this. The interpretation of loss and expression of narrative master plots may change in a similar way to emotions, i.e. they are time limited and elicited by specific events [28] that are relatively perceived or hope, in that they are influenced by various psychosocial factors [41]. To understand this further it is possible that narrative master plots can be examined by assessing psychological adaptation, hope and emotional well-being [29]. This is important, because research is needed which can consider the ability to change certain master plots which may represent a reduced mental well-being, like the hopelessness identified within the chaos narrative master plot or holding out for a total reliance and hope on a medical cure as identified within the restitution narrative master plot. Past research has been able to illustrate this association; denial (adaptation related response) has been reported to have a positive association with emotion related responses, namely with anxiety ($r = 0.4$) and depression ($r = 0.39$) in newly diagnosed people with MS; in contrast acceptance was negatively associated with depression ($r=-0.38$) and anxiety ($r=-0.21$) [42]. This supports the current findings, which suggests that emotions generated by understanding the impact and meaning of MS may drive, or have a greater impact on the expression of master plots pre-acceptance. However, past evidence has also documented that several coping strategies are adopted by people with MS and the current results illustrate that the heroic master plot likely reflects coping strategies commonly adopted by people with MS including planning and pacing, reframing situations, maintenance of dignity or acceptance [29]. For instance, a recent study illustrated that people with MS who face progressive decline choose to think in a positive way and 'reset' what they consider a normal living [43]. This supports the suggestion that effective coping is involved in a more positive narrative cycle and that it is used in order to maintain psychological well-being and be protective against succumbing illness responses.

The results identify that there is a group of individuals with MS who benefit from a group exercise environment as a way of establishing emotional regulation and hope. Exercise appears to supports the different categories of self-management (medical symptoms management, role management and emotional or psychological management) and is considered a much-needed approach to self-management, however it is currently not established for people with MS [44].

The change in expression of different narrative master plots are likely influenced by several psychosocial and environmental mechanisms. The current results identified six mechanisms: (1) Acceptance has been associated with a decrease in negative emotions [42], as such this will likely lead individuals towards an ability to both recognise a need to take action and begin a search-learning process. This is considered essential for psychological adaptation in people with MS [9]. One value of acceptance has been identified as the reduction in need or want to defy or resist the experience of change generated by MS [29]. It is likely that an exercise group provides this and enhances an individual's emotional response modulation [16, 28]. (2) The exercise group provided an opportunity to challenge the adaptation and appraisal of the MS and its impact. Positive re-appraisal [29] has been associated with emotional regulation. Positive reappraisal of one's situation likely occurred alongside membership of the group. This occurs by adopting similar attitudes and values to that of the group, normally by shifting their own values [8]. For instance, the exercise group likely provided knowledge of the benefits of exercise and movement, most notably in relationship to

fatigue, a source of worry for individuals when planning or pacing their day [45]. (3) Self-efficacy appraisals, self-esteem and perceived control [8] are often identified mechanisms of positive change for mental well-being. The exercise rehabilitation group likely benefited the sources of self-efficacy that have a direct impact on mental well-being for individuals with MS46. The process of searching and learning within the exercise rehabilitation group likely leads to a perception of personal competence, a sense of purpose and self-efficacy in the management of MS. Personal competence is essential to the resilience of individuals with MS [43] and to building self-efficacy [17]. This is likely achieved through group encouragement and social comparison. (4) Exercise participation allowed people with MS to focus on what they are still able to do within a planned and paced way. This provided a continuation of some 'normality'. A sense of normality is considered important as it can act to prevent individuals focusing on a pre-determined and limited future often experienced by people with MS [9]. Thus, the exercise rehabilitation group likely provides coping that enables self-reliance and avoids dependence on others, including providing experiences of independence, maintenance of dignity and resilience [29]. (5) The exercise rehabilitation group environment likely provided an opportunity for sharing experiences with related others who can transfer affection [28] and perceived support. This perceived support may provide a distracting focus for individuals and prevented rumination due to the group environment. This has been identified as acting to prevent emotional regulation1 [6, 28]. (6) Positive emotions are likely generated from being in a meaningful and purposeful environment due to the reciprocal relationship of emotions and meaningful activities being undertaken [11]. Further to this, participation in exercise may have a positive impact on mood for instance walking has been associated with increased vigour and improvements in total mood scores [47] or dual improvement of fatigue and depression [48].

4.2 Psychosocial factors which may influence movement in illness narratives

Current results and proposed mechanisms (above) have indicated that movement in narratives can occur. Several factors may be involved with this movement. First, emotions are associated with the chaos narrative and may prevent any psychological distance from an MS related event [19] and create an inability to cope. Indeed, negative affect has been negatively associated with resilient behaviours and an individual's ability to cope [17]. Thus, temporal emotional fluctuations likely change narrative expression. However, it is also possible to experience moments where acknowledgement and hope are perceived, despite loss. One reason for this could be that in the temptation to despair provides the birth of hope [49], so that following the emotional expressions related to chaos it's possible to acknowledge life is not over, thus bring the focus on the loss/es from the past towards focus on the present and future. Second, the relative meaning of the MS related loss and an individual's ability to reframe the loss likely influences emotional regulation. The inability to acknowledge the present circumstances may inhibit the perceived need to undertake the search-learning processes. In addition, emotional suppression [16, 28] could impact individuals with MS and the potential for hidden expressions must be considered. For instance, to express despair can be frowned upon or be perceived as socially unacceptable [50]. Third, the current results identified the importance of particularised hopes and the need for agency and pathways [18]. It is likely the exercise rehabilitation group benefited particularised hopes however finding ways to effective goals setting may be important to movement in narratives [41]. Programs that can accommodate those with moderate disability symptoms are important, this is due to the increasing potential impact of fatigue and emotions from the symptoms of MS [46] on exercise

participation. Indeed, research has shown that those individuals with MS who have a greater perceived disability are likely to experience greater depression and deteriorations in mental well-being [51]. Fourth, hope within the restitution narrative is often focused on a concrete and material, physical or functional outcome. The ability to be restored needs to be widened. For instance, it could consider a psychosocial, spiritual and role related restoration. The exercise group likely impacts on broader psychological constructs like isolation and a sense of belonging [52]. Fifth, the detective narrative is likely adopted when the individual with MS who was once more of a passive recipient of information, becomes an individual with an active interest in learning and understanding what their goals could be. Finally, the words of encouragement used by health care professions influence the individual's ability to cope [53]. The value of social support from others across time is particularly important in this for preventing depression and anxiety in people with MS [51], as well as promoting hope [41].

4.3 Implications

The implications are considered within the Medical Research Council process evaluation framework [54]. Primarily this research suggested that sharing narratives in an exercise rehabilitation context promotes mental well-being by enabling stories which promote coping as part of a particular cycle of master narratives. This cycle is dominated by the detective, didactic and heroic master narratives. This implication may be most appropriate for similar cohorts of individuals. It is important to consider that some individuals with MS may not want to be associated with exercise rehabilitation groups and future work needs to establish, how this may be overcome and when and if such groups would be useful.

Self-regulation may be assisted by; (a) considering stories which are implicitly heroic in nature and are defined by the representation of coping strategies [29] and (b) promoting agency to undertake activities and the pathways that show how continuation despite loss is possible. This is taken from Snyder's hope theory [18] which focuses on particularised hopes and may be captured by a related scale [55]. Alternatively, goal setting and establishing meaning and purpose may help mental well-being as part of the exercise provision [53]. Further to this, shared decision making should be considered a useful way to enable patients to consider goals [52]. A simple tool which captures psychological adaptation and hope [56] alongside emotions (captured by the circumplex model of affect [57]) would likely capture psychological well-being in individuals with MS [29] and represent narrative master plots. Used across time, it may also capture how narrative master plots transition from one to another58. Further to this research is needed that can capture the transition from a primary narrative master plot expressions to dual master plot expressions. Mixed methods approaches to research may be needed to fully capture such processes.

4.4 Limitations

The integration and understanding of the role of physiological processes is limited currently. The heterogeneity of studies used for comparison was limited. There was limited consideration for the impact the environment, setting, culture or instructor had on the illness narratives. There was limited consideration to the impact and willingness to provide socially unacceptable narratives and views by the exercise group must be acknowledged. Current research has not been able to understand the value across different types of MS or stages with the illness or by other factors

like the EDSS scores [59]. Further research is needed to consider this. The optimal exercise dose for people with MS is currently not known [60] and people with different fitness levels may respond differently. The participant's religious or cultural affiliation may impact the results. For instance, a religious group may enhance the individual's opportunity to reinterpret the experience of loss as a service to a higher purpose or ability to be brave in the face of a situation [61]. Disability symptoms and years since diagnosis or exacerbation in symptoms may moderate the impact of exercise on emotion and mood. Recent review evidence has identified this for the benefits of exercise on depression in people with MS [60]. The sample may be self-selected and limited in terms of; (a) an increased ability to undertake exercise in accordance with the trial [27], (b) a greater agency and motivation towards exercise, (c) more positive perceptions of exercise and (d) a limited prevalence of mood disorders possibly due to the limited variation of personality traits [62]. The barriers to exercise need to be considered within the context of the results. For instance, the time devoted to attending an hour group, the experience of fatigue and the political recognition of exercise and relative importance of exercise to the participant impact on its use [52].

5. Conclusion

The current research has been able to increase the understanding of narrative expression in relationship to positive psychological components that are influenced by an exercise group. The research has established a new model that provides unique insight to illness narratives. Further research is needed to establish how the initiation of a group exercise process.

Competing Interests

There are no conflict or competing interests to declare.

Funding

No funding was obtained for this research.

Data sharing statement

Anonymised raw data used within the analysis, additional tables and figures, all techniques and review processes undertaken, and synthesis techniques used have been made available in the supplementary file.

Ethical procedures

Ethical approval was obtained before data was collected within a related project [12].

Acknowledgements

MS Society UK and Oxford Brookes University. The participants that supported this research. Both reviewers of the manuscript for their insightful and beneficial input. This input promoted a significant change in the presentation of the manuscript.

References

1. Dennison L, Moss-Morris R, Chalder T. A review of psychological correlates of adjustment in patients with multiple sclerosis. Clin Psychol Rev 29 (2009): 141-153.
2. Simpson RJ, McLean G, Guthrie B, et al. Physical and mental health comorbidity is common in people with multiple sclerosis: Nationally representative cross-sectional population database analysis. BMC Neurology 14 (2014): 128.
3. Marrie RA, Reingold S, Cohen J, et al. The incidence and prevalence of psychiatric disorders in multiple sclerosis: A systematic review. Mult Scler 21 (2015): 305-317.
4. Giordano A, Granella F, Lugaresi A, et al. Anxiety and depression in multiple sclerosis patients around diagnosis. Journal of the neurological sciences 307 (2011): 86-91.
5. Boeschoten RE, Braamse AM, Beekman AT, et al. Prevalence of depression and anxiety in Multiple Sclerosis: A systematic review and meta-analysis. Journal of the neurological sciences 372 (2017): 331-341.
6. Bruce J, Polen D, Arnett P. Pain and affective memory biases interact to predict depressive symptoms in multiple sclerosis. Multiple Sclerosis Journal 13 (2007): 58-66.
7. Eeltink C, Duffy M. Restorying the illness experience in multiple sclerosis. The Family Journal 12 (2004): 282-286.
8. Thoits PA. Mechanisms linking social ties and support to physical and mental health. J Health Soc Behav 52 (2011):145-161.
9. Soundy A ET. Developing and applying the theory of psychological adjustments needs in patients with multiple sclerosis. In: Watson R, ed. Multiple Sclerosis: Food and Lifestyle in Neurological Autoimmune. New York Elsevier 2017.
10. Benedict RH, Wahlig E, Bakshi R, et al. Predicting quality of life in multiple sclerosis: accounting for physical disability, fatigue, cognition, mood disorder, personality, and behavior change. J Neurol Sci 231 (2005): 29-34.
11. Fredrickson BL. The broaden-and-build theory of positive emotions. Philosophical Transactions of the Royal Society B: Biological Sciences 359 (2004): 1367.
12. Soundy A, Benson J, Dawes H, et al. Understanding hope in patients with Multiple Sclerosis. Physiotherapy 98 (2012): 349-355.
13. Learmonth YC, Motl RW. Physical activity and exercise training in multiple sclerosis: a review and content analysis of qualitative research identifying perceived determinants and consequences. Disability and rehabilitation 38 (2016): 1227-1242.
14. Schneider M, Young N. So this is my new life: A qualitative examination of women living with multiple sclerosis and the coping strategies they use when accessing physical activity. Disability Studies Quarterly 30 (2010): 3-4.
15. Llewellyn H, Low J, Smith G, et al. Narratives of continuity among older people with late stage chronic kidney disease who decline dialysis. Social Science and Medicine 114 (2014): 49-56.

16. Peña-Sarrionandia A, Mikolajczak M, Gross JJ. Integrating emotion regulation and emotional intelligence traditions: a meta-analysis. Frontiers in Psychology 6 (2015): 160.
17. Black R, Dorstyn D. A biopsychosocial model of resilience for multiple sclerosis. Journal of health psychology 20 (2015): 1434-1444.
18. Snyder CR. Hope theory: Rainbows in the mind. Psychological inquiry 13(2002): 249-275.
19. Soundy A, Smith B, Dawes H, et al. Patient's expression of hope and illness narratives in three neurological conditions: A meta-ethnography. Health Psychology Review 7 (2013): 177-201.
20. Soundy A, Condon N. Patients experiences of maintaining mental well-being and hope within motor neuron disease: a thematic synthesis. Frontiers in psychology 6 (2015): 606.
21. Elliott J. Using narrative in social research: Qualitative and quantitative approaches: Sage 2005.
22. Soundy A, Roskell C, Stubbs B, et al. Do you hear what your patient is telling you? Understanding the meaning behind the narrative. Wayahead 18 (2014): 10-13.
23. Smedema SM, Bakken-Gillen SK, Dalton J. Psychosocial adaptation to chronic illness and disability: Models and measurement. A handbook for evidence-based practitioners in rehabilitation (2009): 51-73.
24. Taylor SE. Adjustment to threatening events: A theory of cognitive adaptation. American psychologist 38 (1983): 1161.
25. Pope C, Mays N, Popay J. Synthesising qualitative and quantitative health evidence: A guide to methods: McGraw-Hill Education (UK) 2007.
26. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International journal for quality in health care 19 (2007): 349-357.
27. Collett J, Dawes H, Meaney A, et al. Exercise for multiple sclerosis: a single-blind randomized trial comparing three exercise intensities. Multiple Sclerosis Journal 17 (2011): 594-603.
28. Gross JJ. Emotion regulation: Current status and future prospects. Psychological Inquiry 26 (2015): 1-26.
29. Soundy A, Roskell C, Elder T, et al. The psychological processes of adaptation and hope in patients with multiple sclerosis: a thematic synthesis. Open Journal of Therapy and Rehabilitation 4 (2016): 22.
30. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qualitative health research 26 (2016): 1753-1760.
31. Noblit GW, Hare RD. Meta-ethnography: Synthesizing qualitative studies: sage 1988.
32. Robinson I. Personal narratives, social careers and medical courses: analysing life trajectories in autobiographies of people with multiple sclerosis. Social Science and Medicine 30 (1990): 1173-1186.
33. Boeije HR, Duijnstee MS, Grypdonck MH, et al. Encountering the downward phase: biographical work in people with multiple sclerosis living at home. Social Science and Medicine 55 (2002): 881-893.
34. Driedger SM, Crooks VA, Bennett D. Engaging in the disablement process over space and time: narratives of persons with multiple sclerosis in Ottawa, Canada. The Canadian Geographer/Le Géographe canadien 48 (2004): 119-136.
35. Olsson M, Lexell J, Söderberg S. The meaning of women's experiences of living with multiple sclerosis. Health Care for Women International 29 (2008): 416-430.

36. Aubrey G, Demain S. Perceptions of group exercise in the management of multiple sclerosis. International Journal of Therapy and Rehabilitation 19 (2012): 557-565.
37. Barlow J, Edwards R, Turner A. The experience of attending a lay-led, chronic disease self-management programme from the perspective of participants with multiple sclerosis. Psychology and Health 24 (2009): 1167-1180.
38. Borkoles E, Nicholls AR, Bell K, et al. The lived experiences of people diagnosed with multiple sclerosis in relation to exercise. Psychology and Health 23 (2008): 427-441.
39. Learmonth Y, Marshall-McKenna R, Paul L, et al. A qualitative exploration of the impact of a 12-week group exercise class for those moderately affected with multiple sclerosis. Disability and rehabilitation 35 (2013): 81-88.
40. Barnard D. Chronic illness and the dynamics of hoping. Chronic illness: From experience to policy (1995): 38-57.
41. Soundy A, Stubbs B, Freeman P, et al. Factors influencing patients' hope in stroke and spinal cord injury: A narrative review. International Journal of Therapy and Rehabilitation 21 (2014): 210-218.
42. Sin NL, Lyubomirsky S. Enhancing well-being and alleviating depressive symptoms with positive psychology interventions: A practice-friendly meta-analysis. Journal of clinical psychology 65 (2009): 467-487.
43. Tan-Kristanto S, Kiropoulos LA. Resilience, self-efficacy, coping styles and depressive and anxiety symptoms in those newly diagnosed with multiple sclerosis. Psychology, health & medicine 20 (2015): 635-645.
44. Fraser R, Ehde D, Amtmann D, et al. Self-management for people with multiple sclerosis: report from the first international consensus conference, November 15, 2010. International journal of MS care 15 (2013): 99-106.
45. Newton G, Griffiths A, Soundy A. The experience of fatigue in neurological patients with Multiple Sclerosis: a thematic synthesis. Physiotherapy (2016).
46. Ensari I, Kinnett-Hopkins D, Motl RW. Social cognitive correlates of physical activity among persons with multiple sclerosis: Influence of depressive symptoms. Disability and health journal 10 (2017): 580-586.
47. Southall D. The patient's use of metaphor within a palliative care setting: Theory, function and efficacy. A narrative literature review. Palliative medicine 27 (2013): 304-313.
48. Ensari I, Sandroff BM, Motl RW. Intensity of treadmill walking exercise on acute mood symptoms in persons with multiple sclerosis. Anxiety, Stress, and Coping 30 (2017): 15-25.
49. Marcel G. Homo Viator Introduction to a Metaphysic of Hope. (1951).
50. Little M, Sayers E-J. While there's life. hope and the experience of cancer. Social Science and Medicine 59 (2004): 1329-1337.
51. Lewis V, Williams K, KoKo C, et al. Disability, depression and suicide ideation in people with multiple sclerosis. Journal of affective disorders 208 (2017): 662-669.

52. Horton S, MacDonald DJ, Erickson K, et al. A qualitative investigation of exercising with MS and the impact on the spousal relationship. European Review of Aging and Physical Activity 12 (2015): 3.
53. Soundy A, Roskell C, Adams R, et al. Understanding health care professional-patient interactions in multiple sclerosis: a systematic review and thematic synthesis. Open Journal of Therapy and Rehabilitation 4 (2016): 187.
54. Moore GF, Audrey S, Barker M, et al. Process evaluation of complex interventions: Medical Research Council guidance. bmj 350 (2015): 1258.
55. Snyder CR, Sympson SC, Ybasco FC, et al. Development and validation of the State Hope Scale. Journal of personality and social psychology 70 (1996): 321.
56. Soundy A, Rosenbaum S, Elder T, et al. The Hope and Adaptation Scale (HAS): Establishing Face and Content Validity. Open Journal of Therapy and Rehabilitation 4 (2016): 76.
57. Russell JA. A circumplex model of affect. Journal of personality and social psychology 39 (1980): 1161.
58. Soundy A. Psycho-emotional content of illness narrative master plots for people with chronic illness: Implications for assessment. World Journal of Psychiatry (2018).
59. Noseworthy J, Vandervoort M, Wong C, et al. Interrater variability with the Expanded Disability Status Scale (EDSS) and Functional Systems (FS) in a multiple sclerosis clinical trial. Neurology 40 (1990): 971-971.
60. Dalgas U, Stenager E, Sloth M. The effect of exercise on depressive symptoms in multiple sclerosis based on a meta-analysis and critical review of the literature. European journal of neurology 22 (2015): 443.
61. Seale C. Heroic death. Sociology 29 (1995): 597-613.
62. Bruce JM, Lynch SG. Personality traits in multiple sclerosis: association with mood and anxiety disorders. Journal of psychosomatic research 70 (2011): 479-485.

Citation: Andy Soundy, Helen Dawes, Johnny Collett, Shelly Coe, Sheeba Rosewilliam. Understanding the Importance of Illness Narratives in People with Multiple Sclerosis who Participated in an Exercise Rehabilitation Trial; A Qualitative Study. Archives of Physiotherapy and Rehabilitation 1 (2018): 001-020.